BD SUMHAC
Bleeding Disorders Substance Use & Mental Health Access Coalition

Access to Inpatient/Residential Behavioral Health Treatment for People with Bleeding Disorders

Resources for behavioral health treatment facilities

ISSUE

People with bleeding disorders (BD) are often denied access to inpatient/residential substance use disorder (SUD) and mental health (MH) treatment facilities, despite being medically stable and appropriate for admission. Access to inpatient/residential treatment is a health equity issue. Everyone should have equitable access to behavioral health[1] treatment, regardless of their ability to clot, treatments they use, or state of residence.

The Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) has heard that some facilities are worried about their ability to treat MH and/or SUD in individuals with BD due to the "medical complexity" of their condition, or their use of infusion or injection medication. BD SUMHAC believes that these concerns are, in part, due to a misunderstanding of the condition and current treatments and can be overcome by education of facility staff.

ABOUT BLEEDING DISORDERS

Inherited BD are lifelong genetic conditions with no known cure. Provided that people with BD are stable and maintain their established treatment protocols, there is nothing about the condition that should preclude them from receiving BH treatment in an inpatient/residential setting. People who are stable and well-maintained on their medication typically live in the community and do not require any medical supervision related to this condition. They typically lead full, active, and independent lives. There are no restrictions for activities except participation in contact or collision sports/activities that could result in significant physical injury.

SUPPORTING BEHAVIORAL HEALTH FACILITIES

Most people with BD work closely with a federally-funded HTC or community-based hematologist. People with BD who receive their BD care at an HTC are supported by a multidisciplinary team. Such teams typically consist of a hematologist, nurse coordinator, and social worker, among others. This team will work closely with BH facilities to ensure they have what they need to support their patients throughout their stay.

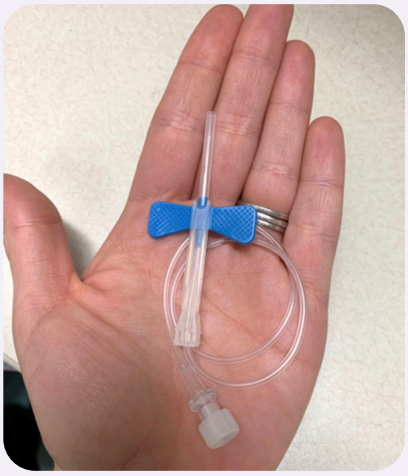
People with BD who are admitted to facilities will typically arrive with their BD resources and educational materials. These materials can also be submitted in advance. BD treatment teams will also typically provide support after their patient has been discharged from the facility, therefore reducing the likelihood of relapse.

Collaboration between the facility and BD treatment team through the admissions process and the stay may include discussions regarding:

- Admission planning/requirements
- Medical clearance documents
- An emergency care plan
- Patient care team resources
- Discharge planning

[1] In this document, behavioral health includes both mental health and substance use disorders.

<< *A picture of a young child self-infusing his BD medication with assistance from an adult. This type of infusion is called an "IV push" since it is given using a syringe and does not require a pump or hanging bag.*



>> *A picture of the type of needle (called a butterfly) that individuals with BD typically use to infuse their medication.*

People with BD are usually taught to self-administer their BD medication during elementary school.

BLEEDING DISORDERS MEDICATIONS

Many people with BD use medication that requires some form of intravenous access, such as use of a butterfly needle for an intravenous (IV) push, or a subcutaneous injection. The infusions used to treat bleeding disorders are fast (usually less than 5 minutes), safe (are not associated with adverse events), do not require IV poles, hanging IV bags, or pumps, and do not typically require any medical oversight or monitoring that would take them away from the facility. The subcutaneous injections are similar to the injections used by individuals with diabetes.

Some individuals with milder types of BD may use oral medication or nasal sprays for treatment of bleeding episodes. All of the aforementioned treatments are extremely effective, and the majority of patients are completely self-sufficient with their care and infuse/inject their own medication when needed. Use of these medications is part of these individuals' normal activities of daily living.

ENSURING HEALTH EQUITY

If a community of people is routinely denied access to BH facilities because of a well-managed health condition, that is not equitable and may be illegal. Specifically, the Americans with Disabilities Act (ADA), requires health care facilities, including inpatient/residential SUD or MH treatment facilities, to make "reasonable accommodations" or changes to "rules, policies, practices, or services" in order to give people with a disability an equal opportunity to access medical care. The ADA protects people with BD, therefore failure to provide a person with BD equal access to inpatient/residential SUD or MH treatment facilities could be considered discrimination.

Examples of reasonable accommodations to ensure equitable access may include:

- **Access to prescribed BD medication**
- **Secure, climate-controlled storage for medication and supplies**
- **Time during the day to receive medication**
- **Allowing the patient to administer (self-infuse or inject) the medication or identifying a provider to administer the medication (staff or external)**
- **Private space in which to administer the medication (e.g., a medication room or a private office)**

If you would like additional information about a specific individual's case, please contact their BD treatment team or the BD SUMHAC advocates at the national BD organizations for additional support:

- BD SUMHAC Advocate at National Hemophilia Foundation:
  Matt Delaney, (212) 328-3780, *mdelaney@hemophilia.org.*

- BD SUMHAC Advocate at Hemophilia Federation of America:
  Mark Hobraczk, (202) 675-6984, *m.hobraczk@hemophiliafed.org.*

If you have any general questions about this information, please visit *www.bdsumhac.org* or contact us at *info@bdsumhac.org*.